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COMMENTARY

"We the Scientists": a Human Right to Citizen Science

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Abstract The flourishing of citizen science is an exciting phenomenon with the potential to contribute significantly to scientific progress. However, we lack a framework for addressing in a principled and effective manner the pressing ethical questions it raises. We argue that at the core of any such framework must be the human right to science. Moreover, we stress an almost entirely neglected dimension of this right—the entitlement it confers on all human beings to *participate* in the scientific process in all of its aspects. We then explore three of its key implications for the ethical regulation of citizen science: (a) the positive obligations imposed by the right on the state and other agents to recognize and promote citizen science, (b) the convective nature of the participation in science facilitated by the right and (c) the potential to mobilize the right in rolling back the unprecedented expansion of intellectual property regimes.

From Thales of Miletus' geometrical theorems to Benjamin Franklin's lightning rod, the history of science is studded with the contributions of individuals who were not professional scientists in the contemporary sense. These intrepid amateurs made observations, conducted experiments or devised methods of investigation that prompted major advances. By contrast, the professionalization and institutionalization of science did not get into full swing until well into the nineteenth century, and when it did so, it had the effect of crowding non-professionals out of the scientific enterprise.

In recent decades, however, there has been a tremendous flowering of non-professional involvement in scientific research. This phenomenon has been dubbed *citizen science* (Bowser and Shanley 2013). Although the term lacks a precise and widely accepted definition, we take it to mean any form of active non-professional participation in science that goes beyond human subject research conducted by professional researchers. In both scope and format, citizen science traverses the full extent of scientific activity. Projects

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range from bird watching, earthquake reporting and the cataloguing of galaxies to do-it-yourself biology and self-experimentation with medical compounds and genetic testing (Nielsen 2012). This broad spectrum of activity is matched by high levels of popular participation. One of the largest citizen science platforms is zooniverse.org, with its various websites so far drawing over a million participants (https://www.zooniverse.org/). Moreover, a work by citizen scientists, sometimes originating in projects devised and led by themselves, has appeared in reputable scientific journals. Indeed, the impact of citizen science is liable to be underestimated because publications drawing on it are not easily identifiable as such (Cooper et al. 2014).

The contemporary flourishing of citizen science can be traced to two large-scale societal developments. One is the high degree of internet penetration around the world and the increasing availability to ordinary people of online tools and mobile devices that can record, store, process and transmit data. In particular, online social media provides the essential infrastructure that sustains global networks of citizen scientists. Another factor is the growing acceptance of the idea that ordinary citizens should be empowered to have a say, and play an active role, in political, scientific and cultural processes that affect them. Today's citizen science movement is the product of this conjunction of unprecedented technological means at the disposal of the general public together with the heightened value accorded to individual participation in all the myriad facets of social life, including those formerly regarded as the exclusive domain of specialists.

Citizen science unquestionably has great potential as a catalyst of valuable scientific innovation. However, it also generates pressing ethical and regulatory concerns that have barely begun to be addressed. These include the potential exploitation of citizen participants in scientific projects, whether set up by fellow citizens or established institutions; the adequacy of oversight mechanisms to ensure the scientific validity and ethical acceptability of research projects in which citizens are involved; the role of informed consent, especially in communities of peers; ownership of personal data and intellectual property issues in cases where discoveries are made; physical, psychological, privacy and other risks, especially where self-experimentation takes place; and the nature of society's responsibility to recognize and foster scientifically valid and ethically sound citizen science.

We urgently need a widely accepted ethical framework—an underlying set of values and principles—to orient us in addressing such questions in an effective and defensible way (Vayena and Tasioulas 2013a). For the framework to enjoy maximal legitimacy, it must be the product of deliberation and consensus among all relevant stakeholders, prominently including the constituency of citizen scientists. In its absence, citizen science cannot realize its full potential as a socially recognized source of valuable scientific knowledge.

1 The Human Right to Science, Participation and a Path not Taken

Like ethical frameworks developed for science conducted by professional scientists, the one adapted to the challenges posed by citizen science must take into account many different ethical considerations. Nonetheless, we contend that the human right to science (HRS) has a central, and radically transformative, role to play in practical deliberation about citizen science.

The HRS is first and foremost an ethical principle, but the one that has acquired political and legal recognition in the post-war era. Article 27 of the 1948 Universal Declaration of Human Rights (UDHR) established a HRS as part of a broader human right to science and culture (RSC). The latter has two limbs:

(1) Everyone has the right to freely participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
(2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author (UDHR 1948).

A prescient 1952 UNESCO document explained the first limb's significance as "not merely adding a final touch" to the UDHR, but stating, for the whole world, *an entirely new principle, whose application may have tremendous repercussions* (UNESCO 1952).

A version of the right eventually appeared in Article 15(1) of the International Covenant on Economic, Social and Cultural Rights (ICECSPR 1966). Although legally binding on parties to the convention, the HRS for the most part lays dormant until very recently, activating none of the anticipated *tremendous repercussions*. However, this situation has changed in the last few years, largely thanks to the UN Human Rights Council. In part, the HRS's emergence from its prolonged slumber is due to activist efforts to invoke it in rolling back the unprecedented expansion of intellectual property rights that have taken place in the post-war period (Shaver 2010).

Yet, even in this revival, a fundamental dimension of the HRS has been neglected. This is the entitlement it confers on everyone actively to *participate* in the scientific enterprise. Such participation goes well beyond merely passively receiving the benefits—such as knowledge, technology, therapies and so on—generated by scientific advances made by professional scientists. Differently put, it treats participation in the scientific enterprise as one of the benefits of science to which we all have a right.

Unfortunately, the UN Committee on Economic, Social and Cultural Rights' General Comment No. 21 on Art 15 (1)(a) of the Covenant offers no extended discussion of participation in science (UNHRC 1966). Equally, the UN Special Rapporteur on cultural rights' report of 2012, on Art 15(1)(b), stresses that "access must be to science as a whole, not only to specific scientific outcomes or applications" (Shaheed 2012). However, it does not elaborate on the participatory dimension of such access. Again, in the AAAS's survey of American scientists' attitudes to the HRS, the question of citizens creating science is briefly raised but left unaddressed (http://www.aaas.org/sites/default/files/content_files/UNReportAAAS.pdf). Yet, the participatory aspect of the HRS is at the heart of what is distinctive about this right. Participation is a key to the *added value* that it brings to our existing entitlements under more familiar human rights, such as the rights to freedom of thought and speech, education, work, health, non-discrimination and so on.

This hypothesis is supported by a closer look at the pioneering 1952 UNESCO study, with the report highlighting "participation by the amateur who works creatively, however humble his sphere, or carries out his own observations in the scientific field (particularly in biology, geology, geography, sociology, etc.)" (UNESCO 1952). Yet, for whatever reason, this participatory aspect was muted or disregarded in subsequent interpretations. It is imperative now to recapture it.

We contend that participation in science, for the purposes of the HRS, should include a broad spectrum of activity that ranges from embarking on a career as a professional scientist, on the one hand, to participation in a standard clinical trial carried out by an established research institution, on the other hand. However, our focus here is on the extraordinarily diverse forms of participation that come under the rubric of citizen science. It is these forms of scientific participation that disclose the radical, but hitherto untapped, potential of the HRS.

Various taxonomies of these forms of participation have been constructed (Shirk et al. 2012). However, for present purposes, an indicative list ordered according to escalating levels of participation includes the following: (a) *crowd-sourced* participation in a project established and governed by professional scientists, e.g. individuals contribute relevant data, observations, etc.; (b) participation in financing, agenda setting or governance in projects established by professional scientists, e.g. crowd funding; (c) collaborative participation in which citizen and professional scientists play a broadly comparable role in the initiation, pursuit and governance of a research project; and (d) in the most radical version of participation, citizens themselves take the lead in initiating, designing and conducting a project—a type of activity that has come to be known as participant-led research (PLR).

Understanding these forms of citizen participation is indispensable in getting a better grip on the content of the HRS. Conversely, armed with the HRS, citizen scientists are better placed to assert their justified claims to recognition and support from the wider society.

2 Why the Right to Participate in Science Matters

The participatory dimension of the HRS is a key element in a compelling ethical framework for citizen science. Some major implications of conceiving of citizen participation in science as flowing from the HRS can be grouped under three rubrics:

A Positive Right Human rights impose duties on us to comply with them. This is what makes them practical guides to action and their violation a matter of grave moral concern. Some duties associated with the HRS are *negative*, i.e. they are duties to refrain from undue interference with scientific activity. However, other duties imposed by the HRS are *positive*. They demand positive action on the part of duty bearers to enable and promote scientific activities or to facilitate participation in them by ordinary people. These may include positive duties to equip people with the basic scientific knowledge needed to participate in science or to provide citizen scientists with various forms of support and recognition, e.g. sources of research funding, access to oversight mechanisms and the opportunity to publish in scientific journals. Given the global character of much citizen science, an important question concerns the extent to which these obligations apply to those outside our own state.

As the 1952 UNESCO report grasped, the revolutionary potential of the HRS is primarily located in these positive duties, especially those concerned with fostering broad-based participation. However, the study of these duties has been neglected. One topic that urgently calls for investigation is the positive duty to provide citizen scientists operating outside of standard institutional contexts with mechanisms of oversight to

ensure compliance with relevant scientific and ethical standards. Only in this way can citizen science responsibly achieve the goal of making a socially recognized contribution to scientific knowledge. However, it is essential that these oversight mechanisms are well adapted to the distinctive character of the activities pursued by citizen scientists, so that they do not choke off a vital source of scientific innovation.

Convective **Participation** It is generally recognized that broadening the participatory base of science governance is a highly desirable objective. Broader participation enhances transparency, accountability and the sense of shared responsibility for advancing the social good. However, wider participation in science governance has proved difficult to achieve in a way that is more than tokenistic (Jasanoff 2003).

In response to this challenge, it is vital to notice that the participation fostered by the HRS has the fertile property of being convective. By this, we mean that citizen participation in one domain of scientific activity spurs participation in other domains. It can do so through various means, e.g. by increasing relevant capacities, motivation and opportunities for engagement with scientific matters. For example, there is evidence that citizen scientists engaged in environmental projects often progress to advocacy roles (Franzoni and Sauermann 2013). Participation in scientific research projects may also naturally lead to citizen scientists playing a role in research governance, whether one specific to the particular project in which they are engaged or one in broader governance, such as peer reviewing for scientific journals or involvement in research oversight mechanisms. Elsewhere, we have suggested that in some forms of citizen science, oversight mechanisms might be operated exclusively by citizen scientists themselves (Vayena and Tasioulas 2013b).

Informed and engaged citizens are more likely to take advantage of existing avenues for making their voices heard in science governance, and they are more likely to push for the creation of additional opportunities for involvement in governance, including at a global level. The result is a mutually reinforcing virtuous circle of participation, as participation in one domain spurs and bolsters participation in others, and vice versa. The noble idea that citizens should play a real part in the *whole of science* can, in this way, come closer to being a reality.

Intellectual Property Reform One of the major reasons for the contemporary revival of the HRS is its deployment as a weapon in combating the massive expansion of intellectual property rights that have taken place in recent decades. The idea is that the expansion of intellectual property entitlements, notably under international regimes such as the 1994 Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), has adversely impacted on the rights of individuals to share in the public good of scientific knowledge (Shaver 2010; Shaheed 2012). The participatory dimension of the HRS stands to make at least two major contributions to this ongoing intellectual property rights debate.

First, the HRS demands that any acceptable intellectual property regime should be configured so as not to unduly burden citizens' capacities to engage in scientific research. It is impossible, for example, to engage in citizen science if relevant scientific knowledge is either inaccessible or prohibitively costly to access. This conclusion may have radical implications for standard intellectual property regimes, such as copyright law, insofar as they erect formidable barriers to citizen scientists accessing scientific knowledge. More

positively, it may reinforce emerging developments that seek to liberalize access to scientific knowledge, such as open access publishing, the activities of the open science movement and the licensing options available under the Creative Commons schemes.

Second, citizen science opens up the possibility of literally thousands of people being *co-authors* of the research outputs and acquiring a corresponding sense of ownership. Pursuing this idea requires that existing intellectual property regimes be imaginatively redesigned. For example, control over scientific knowledge gleaned through some types of citizen science might be better regulated by means of the idea of commons (Madison 2014). The HRS may be a powerful tool in stimulating and shaping new approaches to ownership tailored to the mass participation made possible by citizen science and the legitimate expectations that it generates on the part of citizen scientists.

3 Conclusions

We currently stand at the crossroads of two developments: growing citizen participation in science and a renewed interest in the unexplored potential of the HRS. This is an ideally opportune moment to negotiate how best to facilitate the phenomenon of citizen science within an ethical framework that takes seriously the right of all to participate in, and benefit from, scientific progress. All stakeholders in the scientific enterprise, including citizen scientists themselves, need to be given the opportunity to engage in the dialogue about the duties that arise under the RSC and how best to give effect to them. There is no better starting point for this dialogue than the prophetic words of the 1952 UNESCO report, "The first question of all to be considered in relation to the present state of scientific knowledge is in what ways can the non-specialist take an active part in scientific advancement (experiments, observation of nature, sociological observations, etc.)? How may active participation of this sort benefit the individual and science? How can it be encouraged and promoted?"

The upshot of such a dialogue should be an actionable agenda that includes practical means of addressing the funding, oversight and regulation of citizen science, and the allocation and specification of property rights.

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